Occupation of Cancer Patients: A Challenge to Healthcare Facilities

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Background

Epidemiologic studies based on clinical data from healthcare facilities have taught us much of what we know about cancer today. We are challenged to learn much more as we move into the 21st century. In recent years, coordinated efforts by national organizations in the public and private sectors have led to standardization of data collected on patients with cancer[1] and these efforts hold promise for addressing this challenge. Despite recent advances in data standardization, a number of important data items remain for which a standardized definition and approach are needed but not yet widely available. One such data item is information on the work history of the patient.

Studies have shown that information on a patient's work history, when included in the medical record, can be extremely useful. Data on the occupation and industry of cancer patients have been used to establish links between exposures on the job and certain cancers; substances such as wood dust, pesticides, radium, and asbestos have been implicated in this way.[2] Additionally, some studies have linked cancer and occupation indirectly. For example, a 1984 analysis by the Cancer Surveillance Program of Los Angeles was one of the first to demonstrate from population based clinical data an inverse relationship between the amount of physical activity provided by one's job and the risk of colon cancer.[3] For some carcinogenic substances, national regulatory agencies have used information from studies based on clinical data to set allowable on-the-job exposure limits. Occupational data on cancer patients can also be used to determine whether regulations or other interventions result in decreased cancer risk (see Table 1).

Cancer Data Collection—The Path

Data on patients with cancer follow a well-defined path and fulfill a number of important uses. In the all-important first step of the path, information is written or placed in a patient's medical record by physicians, nurses, admitting office personnel, laboratories, and other sources. In most medical facilities, the next step on the path occurs when a specially trained and certified cancer registrar accesses the patient's medical record to collect specific data items. When aggregated, these data are referred to as the cancer registry. Cancer registries are valuable tools that have been used by medical personnel for decades to improve patient treatment and survival.

In another step of the path, through a nationwide initiative known as the National Program of Cancer Registries,[7] state health departments in 42 states and the District of Columbia collect a subset of standardized registry data from medical facilities for determining the incidence and distribution of cancer cases statewide and for planning and evaluating community-wide cancer prevention and control strategies. The well-known Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute[8] uses registry data. SEER is in place in five states and four additional metropolitan areas. Established by legislative mandate in 1971, the SEER program has collected and published data on cancer incidence continuously since 1973. Researchers, who may obtain certain data after following strict procedures to protect the confidentiality of individuals,[9] are other important users of cancer registry data.

Much of the information collected from the medical record by cancer registrars is of a clinical nature, such as disease site, stage at diagnosis, pathology laboratory results, and first course of treatment. Registrars also search the patient's record for demographic data and information on work history. Unfortunately, the patient's work history is a piece of information that is often missing or incomplete.[10]

After information on a patient's occupation and industry is entered into a cancer registry or other database, it can be processed for analysis using a coding scheme that groups similar job titles into a standardized classification system.

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Table 1

Occupational Exposures and Cancer: Some Examples

Asbestos[4]

Asbestos is a naturally occurring silicate fiber that has been widely used for insulation and fireproofing. Construction workers, shipbuilders, and makers of asbestos products have been most heavily exposed. Although asbestos has been in industrial use since about 1880, usage greatly accelerated in the middle of the 20th century. It was soon shown to be a respiratory toxin, but not until it was studied from 1935 to 1960 was its potential as a carcinogen recognized. Asbestos has now been shown to be a risk factor for lung cancer, mesothelioma, and various gastrointestinal cancers. Before 1972, occupational exposures of 12 fibers per cubic centimeter (cc) of air were permitted. That limit was lowered by the Occupational Safety and Health Administration (OSHA) to 2 fibers per cc in 1972 to prevent asbestosis. In 1985 the limit was reduced further to 0.2 fibers per cc to prevent the cancers associated with asbestos exposure. Even at that level, some malignancies may occur. It is recommended that the use of asbestos be eliminated and substitute materials be used in all applications.

Benzidine[5]

Benzidine is an aromatic amine used primarily in the synthetic dye industry. The industry began in Germany in the mid-1800s with the discovery that dyes could be produced from coal tar. After World War I, the synthetic dye industry flourished in the US even though excess bladder cancer cases among dye workers had been reported as early as 1900. Most dye workers were exposed to a mixture of chemicals and it was difficult to pinpoint benzidine as a carcinogen. In 1950, animal studies provided indisputable evidence of its carcinogenicity. Despite this evidence, uncontrolled exposure continued for many years. OSHA instituted regulations for benzidine in 1973 and, in 1980, OSHA and NIOSH recommended that worker exposure be reduced to the lowest feasible level.

Vinyl chloride[6]

Vinyl chloride is used in the manufacture of polyvinyl chloride (PVC). It has been produced commercially in the US for about 75 years. In 1971, vinyl chloride was regulated at 250 parts per million (ppm); in 1974 three cases of hepatic angiosarcoma, a rare cancer of the liver, were reported in men employed in one vinyl chloride polymerization plant. As a result of this report and subsequent studies, the regulation was revised to 1 ppm. Even this level was recognized as unsafe, but it was the limit that available technology could detect.

Classification makes it possible to group data into usable units. One commonly used classification scheme is the US Bureau of the Census coding system. This system groups thousands of job titles into approximately 500 occupations and 200 industries. The Census Bureau coding system is used by the US Census of Population, by selected state health departments for coding of occupation and industry information on death certificates and for coding the occupation and industry of cancer patients, and by researchers in many fields. The National Institute for Occupational Safety and Health (NIOSH) of the Centers for Disease Control and Prevention (CDC) is currently working on computerized assignment of the Census Bureau codes to text information on occupation and industry. This major advance should substantially reduce the current high cost of processing occupation data.

Work History—The Missing Link

Why is information on the patient's work history often missing or incomplete in the medical record? A major reason seems to be that there is a lack of consensus in clinical settings regarding what information should be collected from the patient, who should collect the information, and when. In the following paragraphs we will address each of these questions and suggest approaches for improved capture of this important information.

What Information Should Be Elicited from the Patient?

In clinical settings it is often not possible to collect the patient's entire work history by means of a detailed interview. When information is collected on the work history, it is most commonly the patient's current occupation and industry. However, because of the long latency period for cancer, it is recommended that patients also be asked to name their single longest-held occupation and industry as a surrogate for work history. A similar approach is used for requesting work history information from family members for recording on death certificates. When summarized in this manner, work history is often referred to as "usual occupation" and "usual industry."

The questions for collecting the longest-held ("usual") occupation and "usual" industry could be structured as follows:[11,12] (See also Tables 2 and 3.)

1. Usual Occupation
   a. Thinking of all the jobs or businesses you have ever had, what kind of work did you do the longest? (Include work done while in the Armed Forces.)
   b. When you were doing this kind of work, what were your most important activities or duties?
2. Duration
   a. How long did you do this kind of work?
3. Usual Industry
   a. In what kind of business or industry did you do this kind of work the longest? (For example: TV and radio manufacturing, retail shoe store, auto parts manufacture, state labor department, farm). (Do not request merely the name of the company or business unless special arrangements have been made for coding of industry from local company names.)

Table 2

Occupation: Complete the Picture!

An occupation entry of "Painter" with no other information gets coded to "Painters, construction and maintenance" (Code 579). The table below shows occupation codes to which painters can be assigned if enough information is available.

Occupation entry	Code	Code title
Painter, house	579	Painters, construction and maintenance
Painter, aircraft	759	Painting and paint spraying machine operators
Painter, animated cartoons	194	Artists, performers, and related workers not elsewhere classified
Painter, brush	789	Hand painting, coating, and decorating occupations
Painter, landscape	188	Painters, sculptors, craft artists, and artist printmakers
Painter, photographic studio	774	Photographic process machine operators
Painter and body man	514	Automobile body and related repairers
Painter and paperhanger	583	Paperhangers

Table 3

Industry: What's Happening?

An industry entry of "Construction" with no other information gets coded to "Construction" (Code 060). The table shows industry codes to which workers can be assigned if enough information is available.

Industry entry	Code	Code title
Construction equipment (wholesale)	530	Wholesale trade: Machinery, equipment and supplies
Construction, general contracting	060	Construction
Construction machinery (manufacturing)	312	Manufacturing: Construction and material handling machines
Construction materials (retail)	580	Retail trade: Lumber and building material retailing
Construction camp	060	Construction

b. Was this manufacturing, retail sales, wholesale sales, service, construction, repair, or other?

If the patient was ever in the workforce, entries such as "retired," "disabled," "unemployed," or "housewife" should not be accepted as a surrogate for work history, even though they may reflect the patient's current employment status.

Who Should Collect Work History Information?

Ideally, all patients would have readily available in their medical record a detailed environmental exposure history that includes all jobs they held. A recent Institute of Medicine panel recommended such an approach.[13] Many physicians do collect work history as part of a complete medical history. However, even when collected the information is not always recorded in a uniform format and in a readily accessible location. Until an ideal situation is realized, occupation and industry information could be collected by hospital personnel who have responsibility for recording basic demographic data on patients. Experience with collecting occupation and industry data for death certificates and for special studies suggests that staff members can be trained to collect this information from the public. Such an approach would ensure that the data are available for all patients in a uniform format. Logistical problems are posed by this approach, however. Questions such as who should train the staff members, at whose expense, in what format the information should be recorded, and other questions remain to be explored at most facilities.

When Should the Information Be Collected?

This issue also poses logistical dilemmas. It hardly seems necessary to elicit usual job information from a patient at every admission to a hospital or outpatient center; however, with the current structure of many clinical record systems, unless the question is asked at every admission the information may not be available when data are captured regarding a specific diagnosis. As computerized and networked clinical record systems become more sophisticated, information on work history may evolve as data items that could be collected at enrollment into a health system and updated periodically. However, until such enrollment data become routinely available, it may be appropriate to collect the information at the time of each hospitalization or admission. Such decisions regarding integration and availability of data collected at each hospitalization or admission and that which could be collected only periodically are some of the many challenges facing information system professionals in the immediate future.

We may be moving toward a standard computerized patient record that reliably contains information collected only periodically as well as information collected at each encounter with a healthcare system.[14] It is to be hoped that we are also moving toward a greater awareness on the part of healthcare providers of the importance of environmental exposures, such as those that can occur at the workplace, to the spectrum of health and disease. Both of these potential enhancements are likely to improve the availability of data on patients' work histories. During this time of change, it will be particularly important to keep at the forefront an awareness of the many and varied uses for clinical data. We need enhanced communication between groups that collect, process, and use data, and we also need cost-effective, nonredundant methods of data capture. A dialogue has begun, but much work remains to be done. Information managers bring a unique perspective to these issues and will be critical to planning and implementing these and other necessary improvements to healthcare data management.

Notes

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9. Note: Required by Cancer Registries Amendment Act (PL 102-515), enacted October 24, 1992.

10. Swanson G.M., A.G. Schwartz, and R.W. Burrows. "An Assessment of Occupation and Industry Data from Death Certificates and Hospital Medical Records for Population-based Cancer Surveillance." *American Journal of Public Health* 74 (1984): 464-7.

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14. Dick R.S. and E.B. Steen, editors. *The Computer-based Patient Record: An Essential Technology for Health Care*. Washington, DC: National Academy Press, 1991. ◆